AGING 2000

CASE STUDY

by

Renee Rose Shield, Ph.D.
and
Edward W. Zesk

December, 1997

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GENERATION OF THE CONCEPT.

In late 1989, a small group of people met and discussed plans to create a local research project as the first step in implementing state-wide reform in health care for the elderly of Rhode Island. Ira Magaziner, an international business consultant who was known in Rhode Island for having designed the "New Curriculum" at Brown University in the 1960s' convened the group at the Faculty Club at Brown. He enlisted the aid of the Reverend Charles Baldwin, (retired) University Chaplain at Brown, who had worked with him on curriculum reform and the anti-Vietnam movement.

Baldwin was a reformer in his own right. With others in the 1960s and '70s, he had formed Hospice Care of Rhode Island, and created the Interfaith Health Care Ministries to teach pastoral care through a consortium of the religious organizations in the state, the hospitals and the medical program at Brown

Magaziner and Baldwin were concerned that the steep rise in health care costs in the United States was a severe problem for the nation if it continued

unabated. They talked with leaders in the state--the directors of the state Departments of Elderly Affairs and Health, various senior members of the business community, the Governor, the congressional delegation, the dean of the Brown Medical School--and they had the same concerns. Magaziner decided to hire a small staff to go ahead with his idea, and the people he talked to formed the initial 20-member Organizing Committee.

The initial staff members were Renée Rose Shield, Ph.D., a cultural anthropologist; Joan Retsinas, Ph.D., a medical sociologist; Ed Caron, an attorney and former insurance executive; Marge Tarmey, a political aide to a former governor; Marsha D. Fretwell, M.D., a crusading geriatrician; Christine Heenan, a young former policy aide to the governor; and Chip Young, a political writer with non-profit public relations experience. Shield and Retsinas had recently published books about nursing home care, and Fretwell had written numerous papers about improving medical care for the elderly. This small staff would be joined by people with diverse experience in government policy, law, public relations, and business as time went on.

The staff initially expected the study and report would be accomplished in six months. Magaziner envisaged two more phases: "Phase II, July through December 1990: Raise funds to implement the models; lobby for necessary legislative and administrative changes; build a consensus to try the committee's proposals and organize a coalition to implement the program. Phase III, January through June 1991: Begin implementation" (memo to Organizing Committee, 1/3/90).

Magaziner funded the first phase by forming a new company, SJS, that provided space and support for the project. The program, soon to be named "Aging 2000," would be carried out under the auspices of the Interfaith Health Care Ministries, in order to provide an ecumenical, non-profit and non-political foundation for its operations. Magaziner made donations to Interfaith Health Care Ministries to fund the project.

As this effort started, Magaziner noted in his memo to the Organizing Committee that:

> "Though I will provide funds, I expect that the ad hoc committee and the Board of the Interfaith Health Care Ministries will have ultimate authority over the study, its content and its dissemination. I see my role as being a catalyst and will influence the process and report only in so far as I can persuade the committee and the Board of Directors of my ideas, just as any other committee participant" (memo to Organizing Committee, 1/3/90).

Magaziner further planned to keep the committee open to people who were interested in joining the effort. Luncheon meetings were held every month or so for the staff to present research findings to the growing committee, which by the completion of the report in 1991, numbered 160 people throughout Rhode Island.

A memo from Caron in the early days stated themes that would become more prominent as time went on:

"The project should define an approach to health care through the eyes of the users, not practitioners or administrators; the project needs to produce a true delivery 'system' design that makes better use of existing health care expenditures to meet these users' needs, the project should be sufficiently innovative, flexible and bold to warrant attention as a possible national model, [and] the project needs to be undertaken and completed in 1990, given the unprecedented worry over our health care system all the way to the White House, the dearth of new ideas and the unique size and demographics of Rhode Island as the most attractive laboratory to pilot a new model" (memo to Health Care Research Study, 2/2/90).

The Committee agreed on several crucial points. The existing health care system had severe problems, and a unique opportunity existed at the time for Rhode Island to become a model state by proposing something fundamentally different. Rather than do something piecemeal, the Committee also was committed to overhauling what currently existed on a broad scale, and redesigning it so it worked better. Finally, the users of the system, the elderly, in order to be satisfied by what resulted, needed to be vitally involved in the process: the research, the design, as well as the implementation of the new model.

The Committee was strongly committed to bringing about change through a grassroots movement. Reform would be pushed by consumers and providers from the bottom-up and not imposed by state government from the top-down. Combining systemic change and grassroots involvement was a totally different

way of approaching health care reform and had never before been attempted at a local level.

Rhode Island provided a convenient laboratory in which to launch a project. Small and compact with centralized state offices and records located in Providence, Rhode Island is manageable to study, though historically harder to reform. In 1989, Rhode Island was tied for 2nd place in the proportion of elderly over age 65 in the nation and was then, and eight years later, is still the first in the percentage of those over the age of 85.

The study process would describe the health care system for the elderly as it currently existed in the state, enumerate what it cost, and describe how users and recipients of the services believed it did or did not work. This required understanding what the local and national services were, who received the services and why, how they did or did not meet the perceived needs, what amounts were spent, where the monies originated, and how they were used. A core part of the study would be based on open-ended interviews with people who participated in the system. These interviews would describe how the system functioned (or didn't) from personal, first-hand experience. No blueprint for solutions was postulated at the beginning.

In the late 1980's it appeared that the time was right for such an initiative. Rapidly rising health care costs were straining state and federal budgets, reducing the ability of American companies to compete successfully and leading to labor unrest as workers fought management to stave off cuts in health care fringe benefits. It was becoming more widely understood that the nation's health

care delivery system was in crisis and in need of an overhaul. Magaziner and Baldwin chose the over-65 population as the target group for the reform initiative they hoped would flow from the research because universal coverage already existed through the Medicare program and because the elderly were the largest consumers of health care in Rhode Island. They accounted for over 38 percent of the health care expenditures and over 59 percent of all public health care dollars spent in the state (Aging 2000, 1991).

It already was clear that while the American health care system and the way it is financed may have been suited to the management of acute illness, the current medical model did not serve the needs of the older person. Because they are likely to have multiple and complex chronic conditions that impede their function, as well as reduce their capacity to manage stress, the elderly often are more vulnerable to the aggressive atmosphere and impersonal routines of the hospital setting than are younger persons. As the health care system became more fragmented, less personal, and more technologically-driven, the high-quality, patient-centered caregiving that older persons particularly seem to need or want was rarely available. Lower-cost, low-tech, supportive services that enhance functioning and help prevent or delay institutionalization of older people in the community, were generally not reimbursed by Medicare. Therefore, the health care system labored with the irony that it produced many of the acute hospital episodes that often reduce an older person's overall functional ability and did so very expensively.

The first product envisaged by the Magaziner, Baldwin and the research team was a report, jargon-free and understandable by all, to be made up of six parts:

- the definition of the national problem;
- the Rhode Island example in detail;
- the historical overview of how the problem evolved socially and legislatively;
- examples of what works well in the nation and internationally (drawn from visits to best practice sites);
- a conceptual overview for reform in Rhode Island; and
- specific ideas of how to implement reform in Rhode Island via legislation, federal or state waivers, and the like.

Following the completion of the report, Magaziner imagined creating a video companion piece. The team would publicize the report with op-ed pieces, a short summary of the report, and the video, and hoped these would generate financial and grassroots support to implement the specific proposals in the report. Rhode Island could be a model state for the nation.

Magaziner had a history of reform challenges behind him, some successful, some not, and he felt he had learned from his mistakes. In addition to his work at Brown, which though controversial, had made Brown the "hot" school it since became, Magaziner had led a less successful revitalization effort in the city of Brockton, Massachusetts. He also was well known in Rhode Island for proposing a bold economic plan for the state which identified the industries that Rhode Island could exploit to become financially successful in the future (the

Greenhouse Compact). However, when the citizens voted on this proposal, it was defeated decisively. Apparently, voters had the perception that state leaders would individually profit by it. Additionally, Magaziner had just chaired and co-authored a study for the Commission on the Skills of the American Workforce.

The most important lesson Magaziner took from his pro bono endeavors as well as his successful business consulting was the need to intimately involve the frontline people in both the analysis and in the creation of the solution of the problem at hand. This would not just be a study, insulated and removed from the actual people who provided or received healthcare services: it would use the practitioners and the elderly as the firsthand witnesses to both the litany of problems and the good care they experienced, as well to form the wellspring of innovative solutions. Further, it was a report that would serve as the general framework of principles and recommendations to guide specific implementation projects.

THE RESEARCH PROCESS.

The research consisted of several key components:

- long, open-ended interviews with users and observers of the health care system, such as the elderly, family members, health care professionals, administrators, health care researchers, and others, such as ambulance drivers, volunteers, meal site workers, senior center personnel, housing managers, etc.;
- interviews with local and national health care experts;

- a thorough analysis of the monies in the system, tracking where they come from, and how they are used, to ascertain where the waste and gaps lay, including a detailed cost analysis of some of the institutions of elderly health care--hospitals, nursing homes and doctors' offices--in order to understand what the costs are and how they are driven;
- roundtable discussions and focus groups with different kinds of participants in the system;
- an understanding of best-practice models throughout the country as well as an analysis of the health care systems of Great Britain, France, Germany and Sweden; and
- monthly discussion and review of research findings to date with the growing Aging 2000 committee.

Open-ended interviews:

The research team believed that the most reliable information originates in the actual experiences of the people who are the most closely involved in the health care system as it currently operated. Therefore, the team sought to interview as many of those people, in as diverse a way as possible, to ascertain the various points of view on the system.

People were selected for interviews by using the "snow ball technique." Key informants suggested names in various provider and user groups; those people were interviewed and in turn, they suggested additional people to interview. In addition, staff carefully chose field sites, as well as consumer group

and individual interviews to reflect the geographic and economic diversity of older Rhode Islanders.

The interviews were semi-structured and open-ended, generally averaging about an hour in length. Nursing home residents, participants in meal sites, senior center members, family visitors, tenants in senior housing, members of senior voluntary associations, certified nursing assistants, nurses, state department administrators, housing managers, day care participants, senior van drivers, meals on wheels volunteers, doctors, nurses, activity coordinators, social workers, health care researchers, clergy-- a total of 671 people from around the state who were affected by or participated in the delivery of health care--were interviewed to help provide a fleshed-out and complete picture of the diverse experiences and perceptions that would highlight strengths and weaknesses in the system. (A detailed breakdown of interviews entitled "Who We Have Heard From" is attached.)

Questionnaires were deliberately avoided because they would implicitly suggest how respondents should talk about the system and would therefore prejudge the subject. The idea was to allow people to decide the problems and resources of the system without imposing the constraints of a priori categories upon them.

The interviews were conducted by members of the staff who then wrote them up in narrative fashion. They took place wherever people lived and worked. Information was also gleaned from testimony presented at public hearings on issues of concern to the elderly. In addition, the research team rode on senior

center vans, met with social workers, made rounds with visiting nurses, visited hospice patients, and interviewed doctors. Staff discussed the findings and discovered patterns in the perceptions and experiences reported. The patterns of the interviews were then presented to the monthly meetings of the Aging 2000 committee for their comments and input.

Though the Aging 2000 staff began with the perception that something was deeply wrong with the health care system as it currently existed, they were fundamentally committed to a non-judgmental tone in conducting the research. This belief formed the basis for using the open-interview process as the main approach to understanding the strengths and weaknesses of the system. The research team believed that health care providers were striving to do their best in a system that often constrained them in bizarre and unexpected ways. It became increasingly apparent that everyone in the system worked hard to improve the care of the elderly, but this work often occurred in spite of or contrary to how the system encouraged or required people to behave. There were strong indications of unintended consequences of good intentions gone awry, and people were perplexed and frustrated with the inefficiencies that the sprawling system engendered. The research team was continually impressed with the good will and abundant energy of people trying to provide the best care possible under difficult circumstances.

Numerous examples of problems were identified through the interview process. A home health nurse described how a patient was repeatedly hospitalized for respiratory distress, but because certain minimal requirements of

the patient's blood oxygen capacity set by national Medicare policy to authorize the portable oxygen at home to alleviate the problem were not met, the patient was not eligible for this device. Thus, the patient was sent home repeatedly, suffered frequent respiratory crises, and was repeatedly readmitted. To help this patient qualify for the portable oxygen which would ensure that the patient was treated efficiently, safely, comfortably, and inexpensively at home, she had the patient walk briskly up and down the corridor rapidly so that his oxygen levels would meet the requirement for authorizing the device.

Interviews such as this one provided dramatic testimony that practical, common-sense solutions for medical care were ignored, driven instead by distrustful, rule-bound constraints that caused people to devise elaborate machinations to avoid or circumvent the troublesome regulations. This gaming of the system was fundamentally undermining trust in it.

The diverse perspectives reflected in these interviews revealed a complex, detailed picture of how health care was organized and experienced in Rhode Island. Some respondents liked parts of the system that others found objectionable, and people varied in their opinions, their experiences, and the subjects they chose to emphasize and talk about. Nonetheless, patterns began to emerge after numerous individuals described their points of view. Stories seemed to repeat themselves; frustrations with the system came from older persons as well as from state health department officials, from nursing assistants in nursing homes to their own registered nurse supervisors, from family

caregivers and van drivers to state Medicaid and health department administrators.

Interviews with Local and National Health Care Experts:

The research team interviewed experts on health care policy, gerontology, economics, and related fields to gain an overview and a context for what was being gathered and learned by the Rhode Island example. This effort helped to put the interview data into perspective and to identify the uniqueness of Rhode Island, as well as its relevance to experiences in other states. Individuals who directed and/or designed best practice initiatives throughout the nation were interviewed as part of this process, as well, in visits to these sites.

Analysis of the Monies:

To dovetail with the interview data, corporate strategy consultants who were added to the research staff, developed a strategic cost analysis that involved the gathering of data of:

- total costs of all health-related activities in Rhode Island and analyzing how those costs were accumulated;
- internal cost structures of three hospitals, three nursing homes, six physicians' offices, and one home health care agency;
- the time and motion study of tasks performed by nurses, nursing assistants, hospital x-ray and other technicians, and other hands-on workers at these institutions;
- in-depth interviews with workers in departments such as medical laboratory, radiology, and pharmacy, as well as the administrative department; and

- specific services delivered to nearly 5000 hospital patients.

The project examined patient care delivered to elderly patients in two tertiary-care teaching hospitals and one small community hospital in the state. Because the teaching hospital served a high proportion of very sick, older and poorer patients, the results were skewed toward a higher intensity of care than was usually performed in other hospitals. In these facilities the staff examined detailed costs and time allocation reports and tracked nurses over 23 shifts, including day, evening, and night shifts. Interviews with nurses before, during, and after the observations supplemented and refined the coding of activities.

Aging 2000 staff kept detailed records and placed aggregated time expenditures into categories that clearly described patient care and administrative activities. The categories were derived from the behaviors observed, rather than superimposed on the data beforehand. This philosophical orientation to the research was consistent with the avoidance of questionnaires in the interview stage. For example, nursing activities that involved hands-on care, medication preparation, or professional communication were grouped as direct caregiving tasks. Another category, called administrative and indirect caregiving, was created to identify time spent filling out charts and other medical forms, personal time, and administrative interruptions (e.g. finding missing supplies, tracking missing test results, or untangling scheduling mishaps). Time spent tracking information requested by physicians and providing care to patients assigned to other nursing staff were placed under the category of direct caregiving tasks.

By tracking nurses during their shifts, Aging 2000 staff could understand descriptively what events, tasks, and other activities comprised an eight-hour shift. Nurses grew accustomed to being shadowed once they understood the project's purposes and intent: to gain an understanding of how care happens. These observations were vital in validating anecdotal stories heard in the interviews. For instance, when countless nurses stated that they felt more like secretaries than caregivers because of the paperwork they were required to complete in order to comply with regulations, the actual time directed to this activity was documented, and it supported their complaints.

The research team also examined the accounting and billing records for twelve Rhode Island nursing facilities. In addition, Aging 2000 staff analyzed the cost behavior at three facilities, two non-profit homes located in Providence, and a privately owned facility located outside the metropolitan area. In these facilities, nurses and nursing assistants were observed during 36 shifts on 21 skilled-unit shifts and 15 non-skilled unit shifts. As in the hospitals, the purpose was to understand the finances of the nursing homes and to objectively see how time was actually allocated to different tasks on each nursing unit.

Finally, the research team analyzed costs in six physicians' offices, including a group practice of 23 physicians, three practices shared by two physicians, and two solo practices. The physicians included a general surgeon, an oncologist, several primary care physicians, and a podiatrist. These offices employed approximately three people, usually a medical assistant and an office

manager, to support the work of each physician. In addition one home health agency's costs were studied.

Round-table Discussions:

Round-table discussions and focus groups were held with varied groups of people. As a supplement to individual interviews, these meetings dramatically highlighted how members of a common group agreed and disagreed about particular issues which were discussed and elicited their ideas for potential solutions. The following are examples of some of the groups that were convened in this way.

A group of pharmacists argued among themselves, for example, about what they thought drove the prices of pharmaceuticals, how they were struggling to survive, and what they thought would solve the problem. A group of certified nursing assistants on the day and evening shifts discussed their personal satisfaction with caring for old people and commiserated about overbearing nurses who did not understand how much time each task took. A table of elderly diners at a meal site in a senior center complained about high medical costs and how much trouble they had with the limited transportation services in the state. A diverse group of physicians, ranging from primary-care doctors to surgical subspecialists bemoaned the increasing Medicare paperwork requirements and how they had to hire additional staff, and buy new computers and continually update software to process forms and resubmit claims for reimbursement. Some primary care physicians told others that they were leaving the state because they could not make ends meet. Clergy members discussed how to create an "ethics-

driven health care system" and reviewed what they considered to be some of the required elements to be included in such a system.

Best Practice Models:

An ad hoc member of the research team traveled to Great Britain, France, Germany, and Sweden and over the course of several weeks conducted interviews of government and policy personnel, made site visits to hospitals, nursing homes, and innovative health care models, and collected data and information about each country's initiatives.

Other members of the team went to local and national sites to learn about national and state, public, private and public/private efforts at redesigning health care for the elderly. Some of the sites visited were Connecticut Community Care, Inc., the Lazarus Project in Minnesota, the Wisconsin Community Options Program, On Lok in San Francisco, Maryland's Senior Care and Geriatric Evaluation Service, and Pennsylvania's Pharmaceutical Program for the Elderly.

Monthly Discussion and Review: Committee Participation

As research progressed, the Aging 2000 team met with the ever-larger Aging 2000 committee to present findings of the interviews, focus groups, cost studies, and best practices. As the data and impressions were presented, members of the committee offered their comments, suggestions, and critiques. This feedback helped the staff focus and continually reorient their efforts to reflect the committee's interests and experiences of first-hand expertise. This procedure both broadened and focused the staff's efforts. Magaziner led the meetings and attempted to coordinate and summarize the gist of the comments so that

coherent conclusions could be elicited from the variety of responses. Staff members were directed to talk to specific individuals or go to specific places for contrasting cases, different models, or alternate experiences. As the committee members responded to the findings of the research team, the scope of the research broadened and also clarified the directions in which to proceed.

During the process much was required of the committee members. Though they received a free lunch at the monthly meetings, their volunteer efforts on behalf of Aging 2000 were significant. At one point in the research phase the committee was divided into approximately nine groups. Each group of varied individuals met separately with Magaziner and other members of the staff to brainstorm what they thought solutions to the health care problem might be. They argued with one another--consumer, physician, nursing assistant, housing supervisor, Medicaid director, hospital administrator, meal site coordinator--about what they thought would or would not work in a new system that corrected the problems of the current system.

One year after the research began, the committee was asked to attend a two-day retreat. The committee was divided into work groups, according to individual interest. Each working group discussed problems and devised solutions on one topic. One group worked on education and training; another discussed constructing an ethical framework for health care; a third evaluated ways to coordinate patient clinical information electronically in order to make information-gathering more efficient yet preserve patient confidentiality. Another group came up with innovative housing options for the elderly. The groups which

comprised this retreat emerged with concrete recommendations and work plans and continued to meet for several weeks after the retreat. Their work constituted the basis for several of the chapters in the final report.

Committee members also worked hard in reviewing the draft report. Each staff member was assigned ten or twelve committee members. Staff members pursued each committee member vigilantly (some called it harassment) for critiques on the writing and the content of the draft. Committee member suggestions for changing content, altering conclusions, offering alternative ideas, and rethinking conclusions were discussed by staff and incorporated in the final version of the report. Ultimately, 146 committee members signed the document, signaling their agreement with the basic premises and conclusions of the report. The report was published in December, 1991, two years after Aging 2000 began.

RESEARCH CONCLUSIONS AND RECOMMENDATIONS.

The report identified basic problems in the health care system for the elderly and made broad recommendations for their solution. The seven problems were:

- Poor information flow and work organization impede the delivery of quality care.
- Administrative and regulatory requirements hinder professionals who attempt to offer responsive health care, and frustrate and confuse patients.
- Medications are too costly and too often misused by elderly patients.

- Medicare and Medicaid reimbursement policies force many elderly Rhode Islanders to give up their homes and become institutionalized as they age.
- The lack of education and training about the aging process hinders the ability of consumers, caregivers and providers to respond appropriately and effectively to the overall needs of elderly consumers.
- The cost of health care continues to climb faster than the rate of inflation.
- No clear ethical principles consistently guide medical decisionmaking.

The five recommendations of the report included four to form the basis of all Aging 2000 programs to be implemented. The final recommendation described three models for the delivery of services, all to adhere to the fundamental Aging 2000 principles. The report stated:

> "The recommendations presented here are intended to spur a process of reform that leads to significant improvement in services. They offer starting points. They set a direction. They will evolve through experience and the ideas of those who join in the dialogue initiated by this report" (Aging 2000:15-1).

The recommendations were the following:

- The system should be founded on ethical principles. Explicit ethical guidelines should form the delivery of health care to all elderly residents and ensure that access to health care be open to all those over age 65. Older patients should be encouraged to make their own health care decisions in partnership with their health care providers.

- A statewide patient information system should be created. A comprehensive clinical information system should be in place for all Aging 2000 programs which would include a computerized database of patient information and security codes to ensure confidentiality.
- High performance work organization should be promoted. By working with health care providers, nursing homes, hospitals, and home health agencies to organize the delivery of care with total quality management techniques and principles, the system will reduce regulatory and reimbursement paperwork, redundant communication, and increase productivity and satisfaction about the work. This would require a federal waiver.
- A system of education and training for health care staff, patients, family members, and the community should be established. A training and resource center should be established to link existing educational resources and programs together to create an effective system of education for older citizens, their families, community members, and professionals.

The three models that Aging 2000 proposed were expected to coexist and provide consumer choice:

- The advocate model would allow consumers to choose their own physicians and other providers, and if desired, an Aging 2000 "advocate" to help guide them through the system. Health care would be paid for through pooling Medicare, Medicaid, and private insurance funds. Each participant would receive interdisciplinary care from a team of professionals who would provide continuity of care over time.

- The total care model would offer a continuum of social, community and health care services through a single organization to both pay for and provide care. The elderly enrollee would have all services organized, funded, and provided by the program and delivered through a community health care center. Preventive, educational and informational services would also form part of this model.
- The home care model would provide a system of community-based services for elderly people residing in their own homes and apartments and wishing to stay within the current health care system. Community centers would serve as hubs for home-delivered health and transportation services and expand services currently available under this model.

After the report was issued, Aging 2000 received a two-year planning grant from the Hartford Foundation in 1992 to design how these recommendations would be implemented. The participatory manner in which the recommendations had been devised would be continued into the planning phase. Aging 2000 staff would use the report as a blueprint for interested communities throughout the state to decide how to organize existing services to reform caregiving. Aging 2000 consortia made up of existing agencies, local providers, and elderly consumers began a process of designing how to reform the existing system into an Aging 2000 demonstration project and enact the Aging 2000 principles of the report.

SUCCESSES AND FAILURES OF THE RESEARCH PHASE.

Ira Magaziner brought his unique personality to the process. This had its advantages as well as its drawbacks. Though Aging 2000 avoided publicity in the first two years, word of mouth spread quickly, largely because of Magaziner's name. As more and more people were interviewed in the state, greater numbers of people joined the Aging 2000 committee. People knew that Magaziner commanded respect, that he got things done, and that he generated controversy. Many came because they were genuinely committed to working on solutions to the health care problems in the state and the nation. Others came because they were convinced that the problems were intractable, were certain Magaziner could do nothing about them, but wanted to witness the process. Others came to ensure their place at the table, to ensure that they not be left out, and to see that their competitors did not gain an advantage. Everyone was welcome, and the different agendas, left implicit and unstated, accompanied them.

Everyone felt righteous complaining and itemizing problems, but working on solutions was something new and a much greater challenge to meet. Though the system was unwieldy and had injustices, it was a system that was familiar and therefore one with which the members were more or less comfortable. How committed were the participants to making bona fide efforts to change the status quo? This question could not be clarified until implementation began.

Never before had so many people connected to varied parts of the Rhode Island health care field joined together in a regular fashion to discuss and attempt to solve systemic health care problems for the elderly. Never had consumers

been asked to participate in such an ongoing discussion. These were stunning accomplishments. Whereas health care providers had intermittent, sporadic contact with one another prior to Aging 2000, this reform process enabled people to solidify and build on those relationships in a practical way.

Magaziner's vision was bold enough that many had profound difficulty grasping the challenge to usual ways of thinking about the problems. He also tapped a wellspring of individual fears that genuine change might actually come about through the Aging 2000 process. Though these fears were rarely explicit, they were masked as objections to potential solutions that others devised. Many of the participants had fundamental difficulty envisaging a way to start the system anew. Many participants' perceptions were bound to the current system: when one person would suggest an idea, another would nix it because current rules or structure forbade it. Magaziner's challenge to the participants was to imagine a "clean sheet of paper" upon which to design a new system. Because people assumed the current system was the given and because they had worked out individual ways of circumventing and living with the existing situation, a strong inertia against change persisted alongside the continued push for innovation and newness.

An assumption built into Aging 2000 was that to not spend additional monies in the new system, the existing agencies, services, and providers would be maintained and utilized in new ways. There was an idealistic belief that people who worked at duplicative services could be reassigned to services that were lacking and needed. It was assumed that If one could cut the bureaucratic

tangle of paperwork down to manageable size and reduce the number of people assigned to the reimbursement processes, perhaps these people could be retrained as advocates for the elderly clients. This promise placated many but may not have been realistic. The challenge of thinking about existing services in a new way was difficult for many people to meet.

Magaziner's charisma and authority brought people to the table, but it also induced a certain passivity which was opposed to the essentially activist spirit of Aging 2000. He dismissed the perception that he had a master plan. Yet, when participants raised objections or posed obstacles to the implementation of a far-reaching plan, Magaziner promised, for example, that the necessary waivers could be obtained easily. When officials who had applied for federal and state waivers protested that there were considerable hurdles to be overcome to receiving waivers, he dismissed these concerns and promised that he could bypass traditional routes to obtain them. Though some resented these blanket assurances, the confident assertions also lulled many into thinking that "Ira knows best." Many adopted a wait and see attitude, hoping that he was right. But the passivity that this stance encouraged made it harder to spur the participants to create their own designs to actually implement the Aging 2000 models in the next phase of the project.

Vagueness was a problem that remained to be overcome. Magaziner had encouraged the committee to think broadly and boldly, and left specific details to be worked out later. The lack of specificity was deliberate for the first phase for two reasons: 1) details such as were "where the money was" obscured the large

goals and prevented participants from reaching consensus on the big notions, and; 2) Magaziner had a fundamental belief in the expertise of the participants. He thought Aging 2000 staff should not be the designers of how the implementation of the models should happen, but should instead facilitate the discussion by the front-line players in the field: those providers, payers, and consumers who knew first-hand what to avoid and what to include and had the experience and knowledge to actually put it together.

A problem in the initial phase was that attention was paid to the politics of consensus-building, sometimes to the detriment of the content. What resulted was a superficial unity which left participants wary of one another, knowing full well that the troublesome details were still to be worked out. Vague promises and assurances were made to individuals with the idea that the specific contents would be handled in the future to everyone's satisfaction. In the meantime, therefore, a general unease persisted.

A further difficulty in this first phase was the relative lack of racial and socioeconomic diversity among the committee members. Though the Aging 2000 staff attempted to recruit broader representation into the committee, it was relatively unsuccessful in rectifying this problem. One important factor was that the lower-paid workers in the system, certified nursing assistants as a prime example, were not permitted to have time off to attend Aging 2000 meetings.

Magaziner's strong leadership style was missed in the next phases of Aging 2000. When it was time for the existing agencies, providers, and consumers to design a system, Magaziner was in Washington with the new

Clinton Administration, leaving behind little effective leadership to make decisions, arbitrate disputes, and clarify the course.

Magaziner believed in the expertise and experience of the front-line worker and user of the system and was committed to their working on the solutions. He conceptualized Aging 2000 as a catalyzing agency that would "level the field" among all the players. At the same time, he nonetheless expected that the major powers in the state--the hospitals and the payers--would be the ones to determine the design. He met with them to devise solutions, and they had the expectation that they would be in charge. He did not envisage a scenario in which the smaller agencies would determine how the hospitals and insurers would operate, yet he fostered expectations among smaller agencies when he said Aging 2000 would level the playing field.

People both suspected that there was a plan in mind and resented it when there wasn't.

The promise of the waiver was enticing to many. Though some grumbled that Magaziner did not know the obstacles that lay before him, others hoped that the waivers were as simple to obtain as Magaziner claimed. The idea of obtaining waivers was a critical one. Waivers would provide more flexibility in the regulations and would allow the money to be pooled. Current regulations kept the various systems of health care funding in separate streams; the right waivers would loosen the onerous regulations and allow local authority to allocate the same amount of money with more discretion.

The history of health care financing had resulted in a patchwork system. Medicare and Medicaid were entirely separate systems though they often served the same populations. An arbitrary division between health and social services existed, though health and social well being are inextricably linked. Each local agency and institution had to account to numerous funders and had little or no discretion about how to use the funds. The requirements of the funders drove the agencies to allocate only certain services within the tightly regulated guidelines. Gaining permission from the government to have the same total amount of money as before but without these constraints--by getting waivers from all the right agencies--appeared to be how the problems of the system could finally be remedied. This was the hope.

TRANSITION: CONSORTIA DEVELOPMENT 1992

Once the report was finished the Aging 2000 staff embarked on the task of publicizing the report, creating an Executive Summary, writing papers for the Rhode Island Medical Journal. They spoke to groups throughout the state, and invited local practitioners, agencies and consumers to come together to form what came to be called consortia in various regions in the state. Magaziner held general informational meetings to explain the method: Aging 2000 staff would now be facilitators, and the front-line practitioners and consumers were the experts who would design the implementation using the philosophical guidelines and recommendations of the Aging 2000 report.

Inquiries and invitations to speak came from agencies all over the state. One of the first came from a nursing home in Washington County in southern Rhode Island. The administrator was interested in Aging 2000's help in starting a consortium. Aging 2000 and the nursing home administrator generated a list of local agencies in order to invite representatives from them to come to a general informational meeting. Fueled by dissatisfaction with the existing system, people came to the first meetings to learn about the Aging 2000 report and to gain an initial understanding of how and why they would participate.

Magaziner and Caron conducted separate talks with the hospitals and the insurers and developed certain understandings with them. Staff members meanwhile tried to develop the voices of the smaller local agencies and the consumers so they could affect the shape of a new system. Later, as networks of agencies and individuals formed consortia, and the small agencies and consumers were stronger, the hospitals and insurers joined the groups to participate in planning and implementation because no one wanted to be left out.

Magaziner became increasingly involved in the presidential campaign, and when Bill Clinton was elected in the fall of 1992, Magaziner prepared to leave for Washington, DC. Ed Caron, who had been interim director for several months, also left taking a position as Vice President at Providence College. Board members from Interfaith Health Care Ministries appointed a "Project Committee" that was officially in charge of Aging 2000. After a brief search, Jim Thomas was selected as the new executive director of Aging 2000. Thomas was a successful businessman who had a knowledge of finance and had numerous personal

contacts in the state. His experience was helpful to the consortia in designing business plans that would lead to successful implementation.

Aging 2000 staff members asked representatives from senior centers, hospitals, nursing homes and other agencies who were interested in implementing the Aging 2000 philosophy in their own communities the following questions: What is your plan? What would you like Aging 2000 to do to help? What barriers do you see in promulgating your plan? What collaborations have you made now or in the past? What have you done so far, internally, to start the ball rolling? What's your time plan? What are your strengths and resources in putting these ideas together?

Aging 2000 staff members had certain expectations about what to do. A proposal from early 1992 outlined plans that in addition to negotiating with providers who wished to participate in Aging 2000 and developing concrete implementation plans, Aging 2000 would:

- secure government waivers with the help of the congressional delegation;
- develop independent ethical and consumer oversight procedures because "even groups which originate from consumer action or religious or ethical roots, innocently lose sight of their origins as the complexities of day-to-day program implementation overwhelm them [and] administrative expediency can then stifle consumer satisfaction";
- and continue research to develop case-mix adjustment measures for finer-tuned reimbursement capability, to design an outcome-oriented quality assurance program for the demonstration models and provide an ongoing

study of improved work organization procedures in hospitals, physicians' offices, nursing homes and home care agencies.

It was also expected that the different groups that presented demonstration models would "specialize" in some form or other. For example, it was initially thought that one group would plan the patient information system while another would plan the education and training efforts, another one would plan the work reorganization reform while still others would develop the care models.

As it turned out, the providers, agencies, and organizations in Rhode Island which expressed interest in Aging 2000 were also interested in planning demonstration models to provide unified care services to elderly consumers. Each developing group basically wanted to do it all. There was confusion in the first months. New people joined the effort, and they knew little about Aging 2000. The Executive Summary was published and was handed out at briefings and to everyone interested. As inquiries came from individuals and specific agencies, Aging 2000 staff members asked the interested parties to invite neighboring agencies and institutions, and consumers to come together for meetings and to choose an Aging 2000 model which they ultimately wanted to develop in their region. Meetings became a venue in which the history and principles of Aging 2000 were explained. Discussions continued about the history and ideology of Aging 2000 as well as the three models. Many were frustrated about how to make the leap between the conceptual report and the actual implementation, but

everyone was excited about the terrific potential of existing agencies working together in new ways.

Aging 2000 staff's repeated exhortation to consortia members to design a plan met with perplexed questions and a general inability to proceed. People wanted to be shown how to implement the report. There remained the expectation that Magaziner had the plan in his pocket and would unveil it sometime. Further, as discussions continued, the distinctions between the three models seemed to melt away and each consortium ultimately blended the models into one with common key features: the idea of an advocate; the provision of a continuum of services; pooled finances; a way to share clinical patient information; a plan to provide education about aging to providers and consumers; work reorganization; shared ethical guidelines; and consumer empowerment.

The strategy that Aging 2000 staff used in the initial consortia development was to hold general meetings, explain Aging 2000, ask for comments and ideas and continue to meet as a group. The responsibility for creating a structure for the consortium lay with the local group. Aging 2000 staff were available to assist in whatever ways possible, from helping to do mailings to meeting individually with people in their separate agencies and organizations.

Each consortium developed uniquely. This uniqueness was based on the specific geographical, political and cultural factors of the region. The consortium in Washington County in Southern Rhode Island exhibited a feisty independence and energy from the start. The group met weekly at 7 AM; the lead agency went from the nursing home to the local Visiting Nurse Association. Both area

hospitals expressed interest but stayed on the sidelines initially. From the beginning the Washington County consortium had numerous and vocal elderly consumers. Washington County considered itself far removed from the capital city, Providence. Individuals in this consortium exhibited independence and a spirit of self-reliance. They were not accustomed to services coming to them from Providence and they prided themselves on this marker of their identity. This group also had four committed primary care physicians who regularly attended the meetings. The decision to hold meetings at 7 AM was made to allow the physicians to attend, and this scheduling detail kept them there. It seems likely that the relative lack of committed physicians in the other consortia groups over time resulted from the fact that the meetings were scheduled at different and difficult times for physicians. Most physicians were the only group of providers involved in Aging 2000 who were not salaried. They thus lost revenue every time they took time out to attend a meeting.

The Jewish agencies and the Miriam Hospital on the affluent east side of Providence had attempted to form a consortium prior to 1989 and had joined Aging 2000 proceedings with an eye toward eventually reaching their goal of creating a coherent and streamlined continuum of services with an information system that linked and tracked people within it. Aging 2000 lent its services and reignited their dormant efforts. Meanwhile other groups within the Providence area were forming the rough outlines of other consortia. One began from a nursing home-housing complex and another was generated from a hospital physician who wanted to start a clinic in a low-income area located near senior

housing complexes where the tenants had no primary care physicians. Eventually all these groups consolidated to become the Providence Consortium.

The group that came to be called the East Bay Consortium started with an inquiry from the director of a mental health agency in the area. Meetings were well-attended in the beginning by representatives of agencies, some nursing homes, some of the senior housing complexes, and the senior center, but this consortium initially suffered from not having consumers and physicians, and no real concrete steps toward creating a plan materialized for many months. Eventually, a nursing home administrator together with a retired lawyer-consumer shared leadership and mobilized the group. They divided into smaller committees to work on specific tasks inspired by the problem and recommendation list of the Aging 2000 report. The East Bay group eventually linked with a local hospital in a nearby community, but the choice of that hospital was somewhat arbitrary and not entirely successful because many of the consumers in the East Bay area went to various other hospitals.

Writing a business plan became the main focus of each consortium after they were initially organized and had created a basic format for meeting and being a group. Thomas' business background inspired the business plan to go forward. Aging 2000 provided a model framework to follow. Each group was asked to create a name for its consortium, define a mission statement, identify the groups and individuals who were involved, and to work on how the agencies would collaborate and how the services would be organized and provided.

The Washington County Consortium in Southern Rhode Island designed a business plan over the course of several months. As in all consortia, various individuals jockeyed for power over the leadership of the consortium. Aging 2000 staff met individually with the major players to help resolve these conflicts. Ultimately, each of the nascent consortia stayed together because they agreed that what brought them together was their common concern that care for the elderly be improved. Aging 2000 staff reminded them of this core principle at critical times, and this shared value seemed to enable people to work together.

Questions of who would be in charge, which agency would take the lead, how the money would be allocated, how risk would be handled, how the agencies would work together, and manage the money remained difficult and were often left unaddressed in order for the group to continue. Aging 2000 staff attempted to keep the focus of how services should be organized, not on how much money would come in, how the money would be allocated, and who would control it. Talk of money consistently derailed efforts at unity. Improving the care for the elderly was a productive focus that alleviated conflicts and rivalries.

A special consumer strategy was called for. Adelaide Luber, a former director of the state Department of Elderly Affairs, worked with consumers to answer questions, teach them about health care policy, and fortify them as they became active members of the regional consortia.

Each region of the state had its own unique history and configuration. Aging 2000 staff members knew from the outset that it was not possible to have each consortium follow a uniform master plan. What was needed was to

recognize the uniqueness of each geographical region and have each consortium design a plan that would reflect its own values and cultural identity within the philosophical rubric of Aging 2000. This allowed different variants of the Aging 2000 theme to be tested in their areas. How each consortium went about the business of designing its model also reflected the particular members of the group, and especially, the leadership. Each geographical region also had its own history of inter-agency and inter-institutional relationships which influenced future partnerships or alliances. One region had two hospitals, a strong Visiting Nurse Association and not much history of working together. Other regions had strong agencies whose members felt overshadowed and dominated by the hospital in the area. Each region's agencies had developed their own "coping style" and pattern of making do with one another, and Aging 2000 had to adapt to the particular configuration that existed as it tried to mold it in a new, cooperative direction.

Distrust of hospitals and insurers was a common theme among the smaller agencies, particularly at the outset of the consortium process. Nonetheless, each consortium felt it needed the support and collaboration of the local hospital. Each consortium set about to include all the agencies and organizations so that a full range of services that could be available to the consumer.

There was spirited debate about the role of the consumer in each consortium. Consumer empowerment was a mantra that each group espoused. Consumer involvement in the consortia meetings kept the fiscal and health care jargon to a minimum. It took one consumer questioning, "Why would I want to

join a plan that looks like it will be more complicated or respect me less than what I currently have?" to immediately refocus and clarify the goals of the group. When a consumer would ask that the discussion be translated into English, the other participants would struggle to clarify their terms and speak a common language.

Aging 2000 staff continued to consult with experts in the field during the consortium phase. Trips were made to various Program for An Inclusive Care for the Elderly sites and the Social Health Maintenance Organization support contractor at Brandeis, as well as other S/HMOs. As Aging 2000 consortia were organizing themselves and attempting genuine grassroots reform, Aging 2000 staff were trying to ascertain what the ultimate structure of the organization should be. Was Aging 2000 a S/HMO? Should it try to organize all the consortia into a giant PACE site serving Rhode Island's entire elderly population?

Aging 2000 was committed to serving all those over age 65. The original On Lok and other PACE replication sites were for the frailest individuals, community-dwelling elderly who were nursing home certifiable. S/HMOs had a dubious track record of truly integrating services and had to restrict the numbers of participants in order to avoid adverse selection. There was no model in existence that could fulfill Aging 2000 goals.

The future identity of Aging 2000 was constantly debated. Should Aging 2000 fade away after being the catalyst to bring local groups together into consortia that would themselves offer coordinated Aging 2000 health services to the elderly? Should it remain in existence in some kind of advisory, arbitrating

role? Should it be a central organization from which funds flowed? Should Aging 2000 form a public-private partnership with a state department? Board meetings, consortia meetings, and site visits by the Hartford Foundation all struggled to develop ideas for the best role and structure for the fledging organization.

While Clinton's health care reform package was debated in Congress and the country, spurring numerous other plans and substantial discussion and disagreement, Aging 2000 staff and members mused whether Aging 2000 would become one of the regional health alliances that were being proposed. Should Aging 2000 handle the money? Should Aging 2000 deliver services? What should the relationship between the Aging 2000's central office and the Aging 2000 consortia be? How much unity and how much diversity could be contained within the idea of Aging 2000?

By September, 1992, Aging 2000 staff members believed that a rider on a Congressional bill would be the easiest, most bipartisan, and safest way to secure permission to proceed with the kinds of demonstration projects that were envisaged. At the time this was seen as a more expedient and politically feasible alternative to applying for federal and state waivers. Later, when opposition to the Clinton plan brought a legislative activity to a stand still, Aging 2000 resumed work on a waiver document, hoping to submit it in January, 1993, expecting approval by the fall.

In the fall of 1992, there were ten statewide consortia covering virtually every county and municipality in RI. In addition, Aging 2000 was collaborating with Brown's Program in Medicine on a grant to become a multi-institutional,

interdisciplinary Geriatric Education Center (GEC). By the end of September 1992, Aging 2000 had developed a document called, "The Aging 2000 Care Integration Project: the Reorganization of Medical and Social Service Practice in the Care of Older Rhode Islanders," (attached) which spelled out general plans to integrate acute and long-term care into comprehensive service networks [consortia] in order to restructure the way health care institutions operate internally and relate to other institutions, standardize patient information, pool funds from existing funding streams and distribute it to insurer/provider groups based on capitated rates and change reimbursement incentives to focus on disease prevention, reduced institutionalization and broad outcome measures. This document explicitly included the need for waivers from the Health Care Financing Administration (HCFA). It sought 105% of the federal funds that would have been provided for the enrolled Medicare (and/or Medicaid) population for start-up costs, the amount to be reduced to 98% of costs within 5 years.

The CARE Tool.

At the same time, the Aging 2000 staff was field testing in several hospitals and doctor's offices the use of the Aging 2000 CARE tool, designed by Medical Director Marsha Fretwell, MD. This assessment and planning tool contained basic clinical information about an elderly individual. The document listed several "areas of concern" for the patient. The diagnoses were first; next came the number and kind of medications; then the nutritional status, urination, defecation, cognition, emotion, mobility, and care plan maintenance (or patient's

predicted ability to follow agreed-upon recommendations). Each category of concern was assigned a number along a severity scale. Thus, a person who had five or six medications was a number 4 on a scale from 1-6. If the person had mild short term memory loss, he or she was assigned a 2 on the cognition scale. An interdisciplinary team consisting of the primary care physician, the patient, and others such as a physical therapist, pharmacist, and/or social worker, individually and together assigned the person along the scale for each area of concern. Specific goals to remedy or alleviate the person's particular ailments or conditions were set. In some cases the goal was to maintain the person where he or she was. Losing weight, going on an exercise regime, seeing a physical therapist, eating more fruit and vegetables were some of the interventions that would be instituted to maintain or improve a person's overall health. Thus the CARE tool was a way that all the providers and the patient could understand and collaborate in the person's overall condition at a glance, set goals, and over time, track whether the goals had been met. The CARE tool was a simple way to institute an outcomes-based system of accountability regarding the quality of services.

In sum, the use of the CARE tool set up a baseline health status measure for the nine areas of concern, served as a screen for high-risk patients, created an individualized problem list, created individual service interventions which included patient preference, and projected the prognostic health status of each individual.

By February, 1993, the staff was writing the waiver request and establishing appointments with HCFA to discuss the application. The leaders of

the various consortia (called "conveners") had decided to hold regular meetings in order to coordinate their separate efforts and become more unified. By this time Aging 2000 had also outlined a list of "givens." These were a set of assumptions and starting points for all consortia to follow in developing their plans for implementation models. The givens included:

- adherence to Aging 2000 principles of ethical guidelines
- commitment to a common patient information system
- a shared approach to education and work reorganization principles
- serve entire Medicare population
- no eligibility threshold based on income or frailty
- one statewide waiver
- single payer system
- voluntary enrollment
- minimal Medicare Parts A and B services covered
- enrollees must have a primary care physician
- patient advocacy must be an explicit goal of care
- interdisciplinary use of CARE tool
- single functional assessment based on CARE tool
- dispute resolution process must be included
- substantial consumer representation in governance structure

Aging 2000's work plan of February 1993 identified ten "unresolved issues." These were 1) the writing and receiving of the waiver; 2) the development of an information system via the CARE tool; 3) the development of

an education and information system for the consumer; 4) the identification of a governance structure; 5) the development of consumer issues such as advocacy and consumer incentives to stay healthy; 6) the possible merger of some of the consortia; 7) the possible involvement of state agencies in planning; 8) the development of a legal structure for the organization; 9) the identification of which services would be offered in the model; and 10) the development of an ethics system to provide quality control and handle complaints.

The central office of Aging 2000 as well as each of the consortia had by now developed working committees on subjects such as work reorganization, information system, ethics, and education and training. Each consortium had subcommittees working on these and other topics as they developed their plans. Each worked on the local level and then joined together with representatives from the other consortia, as well as designated Aging 2000 staff to develop and unify plans. In keeping with the original focus on grassroots involvement, the Aging 2000 central office deliberately differed to the local consortia to provide the content that they considered relevant.

As the CARE tool was field tested throughout the state, allowing interdisciplinary input into the parameters of the instrument, it was also introduced to the local consortia as a key mechanism to unify services and achieve Aging 2000 goals. It was a way to provide interdisciplinary team caregiving to the enrollees of the demonstration projects that would emanate from the consortia, and it was the vehicle by which clinical patient information would be collected and tracked.

ENTER THE INSURERS: THE DEMONSTRATIONS, FALL 1993.

In September, 1993, President Clinton announced his Health Security bill which set off massive and alternative proposals in Congress. Rhode Island was ready for change since the consortia were in place, and several were ready to launch their experiments in health care reform that had been developed through grassroots research and consensus. Prior to the expected federal approval of waivers, several of the local Aging 2000 consortia were encouraged to develop their own model demonstration projects. While the consortia had been working on their plans, Aging 2000 staff had held numerous meetings with state officials and insurer representatives about their willingness to enter into partnerships. Since it was believed that the waivers were forthcoming, the idea was to reorganize care as much as possible within the confines of the existing system in the meantime. The best way to do this was to work with a payer/insurer that already had some flexibility in its structure. Two models of financing mechanisms were used: a Preferred Provider Network using a Medicare risk contract and a staff model HMO, using a Medicare cost contract. The demonstrations would involve primary care physician practices and HMOs working with providers and elderly through the local Aging 2000 consortia.

Four explicit goals guided the implementation of the demonstration project phase. By gaining experience with the consortia demonstrations, Aging 2000

wished to 1) evaluate the effectiveness of the CARE tool for describing baseline and post-intervention functioning; 2) develop individual care plans which identified appropriate services; 3) develop community-based interdisciplinary care teams to facilitate integration of medical and psychosocial services; and 4) identify ways to improve the documentation and integration of care through improved work reorganization.

At this time, United Health Plan of New England had the only Medicare risk contract in Rhode Island. United received a capitated amount per Medicare enrollee and was free to provide extra services within the capitated budget. United and Aging 2000 entered into negotiations about how to initiate a demonstration project. Washington County's consortium was ready. Its business plan identified the steps needed to begin the demonstration. United agreed to provide some limited funding for possible extra services for those enrollees who chose to enter the demonstration.

An interdisciplinary team was formed. The team consisted of the patient, the patient's primary care physician, Aging 2000's geriatrician, United's nurse care manager, a registered nurse, social worker, physical therapist and pharmacist if the patient was on more than three medications. Other professionals, such as a nutritionist, dental hygienist, and chaplain, were added as needed. The participating hospital and other agencies donated the time of these individuals for team meetings. The team met weekly for two hours with four patients of one participating physician each scheduled for a half-hour conference. United provided some reimbursement to physicians for their time in

the Care Team meetings. Extra services would be authorized by the United nurse care manager and paid for by the insurer if the team and the patient believed that they would help prevent disease or maintain health.

Carol Cummins was hired to manage the demonstration in Washington County, and the design of this project set the tone for the demonstration to follow shortly for the Kent County demonstration which was also in collaboration with United Health Plan. A cadre of eight elderly volunteers was chosen and trained to enroll patients of the four Aging 2000 physicians who agreed to participate in the Washington County demonstration. The training was in collaboration with Phil Clark, Ed.D. of the Gerontology Center at the University of Rhode Island and consisted of approximately 15 hours of education about Aging 2000, myths of aging, advance directives, ethical considerations, the role of the team, and mechanics of how to enroll patients in the project. Enrollees in the demonstration were also encouraged to attend free Aging 2000 educational sessions on how to prevent disease and maintain health. By participating in the Aging 2000 demonstration, the enrollees were agreeing to subscribe to the basic principles of Aging 2000, including being active participants in the maintenance of good health. Enrollees were also encouraged to complete advance directives during the process.

The demonstrations put into practice the key tenets of the original Aging 2000 recommendations. Elderly volunteers, though not technically advocates, helped guide patients through the process. The weekly team meetings would be the basis for the beginnings of a rudimentary information system as well as a way

to institute work reorganization principles for interdisciplinary collaboration; and ethical integrity was enhanced by stipulating the patient's central role in planning and decision-making as well as the creation of an ethical oversight committee for complaints and review. The team, including the patient, would make the clinical decisions and reduce the insurer's role in micromanagement.

Other consortia, in collaboration with health plans, such as Harvard Community Health Plan (a staff model HMO) and HMO Rhode Island; and providers such as RI Hospital, Providence Housing Authority, and Roger Williams Medical Center, developed similar demonstrations over the following months. By the end of 1995 the Washington County, Kent County and Blue Cross demonstrations were completed. The "Final Progress Report" presented to the John A. Hartford Foundation in January, 1996, reviewed the course of the demonstrations and evaluated the experience. Though the Washington County and Kent County demonstrations expected a greater overall enrollment and a higher rate of participation by older seniors than did enroll [192 people enrolled with an average age of 72 and only 32 frail participants (Cummins 1996:1)], much of the evaluation was very positive. Enrollee self-assessment, providers' assessment, team scores, telephone interviews of enrollees, and Care team/physician surveys were used to evaluate the effectiveness of the CARE tool, and over 74% of the respondents rated its effectiveness "good" or "very good" (Cummins 1996:2). Overall survey results showed a high level of participant and provider satisfaction with the Aging 2000 process, with 91% of participants stating that their enrollment had been "helpful," and 95% of the

providers rating the Care Team approach as "good" or "very good" (Cummins 1996:8). The report added that:

> "We also found that formal and informal education, along with the provision of relevant, comprehensible information, is essential in helping older patients to understand their own health status and services available to keep them healthy. Involving consumers as members of their own care planning team, and giving them ownership of their own health information appears to facilitate the process of consumer empowerment" (Cummins 1996:9).

The experience of the demonstrations lent considerable credence to Aging 2000's ability to be a positive influence on how the health plans modified services for the elderly and how important the role of education to overall health status can be.

THE FUTURE STRUCTURE OF AGING 2000.

The year 1994 was one of transition for Aging 2000. The spring of 1994 was taken up with fervent discussions regarding the future shape and role of Aging 2000 in the state. Four basic options were debated at a board retreat in March, 1994. These consisted of Aging 2000 becoming 1) a health care alliance through the necessary federal waivers, contracting with health plans to deliver services, and sharing their risk; 2) a managed care health plan which receives waivers providing network services to the subscribers of local consortia; 3) a senior service corporation which receives waivers and contracts with the local

consortia to provide services through local agencies, controls the funds, establishes standards and assumes the risk; or 4) a state-private partnership which receives waivers, shares risk with the state and contracts with the health plans who in turn deliver services. The third option was favored because it was felt that it provided more control, was able to set guidelines and services by using the existing local consortia, and could negotiate and control costs. However, it was noted that this option meant that Aging 2000 would have to bear risk, compete with the other health plans, and have the high start-up costs and organizational difficulties of a fledgling organization.

In order to pursue this option, the decision was made to apply for incorporation as a non-profit 501(3) organization, independent of the Interfaith Health Care Ministries. An interim board of directors was established comprised of volunteers from among consumers and providers involved in Aging 2000 activities. A committee was created to draft by-laws for the prospective organization.

Practical considerations raised a number of questions about the wisdom of Aging 2000 becoming a Senior Services corporation. The main obstacles were that the Senior Services Corporation option required that Aging 2000 1) satisfy Rhode Island laws to sell insurance; 2) become a hospital, medical, or dental service corporation, each of which was considered politically impossible to achieve; or 3) become a health maintenance organization (HMO) which required developing a network of like-minded providers, having sufficient capital,

developing a marketing plan, and most importantly, perhaps sacrificing the ideals of Aging 2000 to fiscal viability.

Jim Thomas resigned in May 1994 and Director of Operations Barbara Ruffino succeeded him as executive director until December 1994 when she was appointed Director of the R.I. Department of Elderly Affairs by newly elected Governor Lincoln Almond.

In September 1994, Spectrum Research, a Rhode Island based consulting firm, was hired to evaluate the potential future role of Aging 2000. The lead consultant, Harvey Zimmerman, interviewed a number of health care providers, insurers, government officials and opinion leaders in Rhode Island.

Zimmerman's report, "Organizational Options for Aging 2000" (March 1995) spelled out the drawbacks of the various options under consideration, outlined what was considered to be the special strengths of Aging 2000 at the time, and advocated that Aging 2000 instead adopt "a Consumer-Health Care Partnership" approach:

> "Aging 2000 is perceived to have widespread support. It is thought to stand for efficiency and high quality care. It is admired for its ability to achieve consensus among consumers, providers, and payers. Its strengths as an advocate result from these qualities. The reactions of many people in state government to the suggestion that Aging 2000 might consider becoming an insurer is that this would force the organization to soften its principles in order to accommodate its finances. Under the Consumer-Health Care Partnership Model, Aging 2000 would bear no

financial risk. Thus, this role would allow Aging 2000 to continue its mission without the perception that it was compromising its principles" (Zimmerman 1995:4).

The report emphasized how the unique strengths of Aging 2000 were historically and continuously in its role as a positive influence on an improved orientation to elderly caregiving and as an educational resource for consumers, in particular:

> "...the potential of Aging 2000 as an agency that can achieve consensus to sponsor new ideas and develop pilot programs that can affect the ways in which services to seniors are provided was mentioned by representatives from both public and private organizations. The need for education of consumers on appropriate use of preventive, acute, and chronic services and the need to influence physicians to refer to appropriate nonmedical sources of care where appropriate were seen as two areas where the need for change is apparent. This would require Aging 2000 to develop the capacity for needs assessment and case management, but would add educational and training components" (Zimmerman 1995:5).

With Ruffino's departure, the Aging 2000 Board of Directors appointed a search committee in December 1994 to recruit a new executive director. Following extensive interviews with a number of candidates the committee recommended, and the Board approved, the hiring of Ed Zesk. Zesk was the former Senior Vice President of the Hospital Association of Rhode Island, a past member of the Aging 2000 committee and a signatory of the Aging 2000 report. He had extensive experience in health care policy development, legislative

advocacy and public relations. From 1992 to 1994, he had been Vice President of the Greater Cleveland Hospital Association, and the hospitals' representative to the nationally-recognized Cleveland Health Quality Choice Program which developed a public reporting process on medical quality and consumer satisfaction for 30 hospitals in Northeast Ohio.

Zesk joined Aging 2000 in mid-March 1995 and strongly supported Zimmerman's recommendations. His experience in Cleveland with managing competition among health care providers on the basis of quality, and his exposure to well-developed purchasing cooperatives there, convinced him that these concepts could benefit Medicare beneficiaries. He believed that Aging 2000 could be a catalyst in promoting better coordinated care for seniors, creating educational programs for consumers and providers about health and aging issues, helping Medicare beneficiaries to become informed and responsible consumers, and developing performance measures for health plans and providers.

Having received approval to become a 501(c)(3) non-profit corporation, revised by-laws were adopted and a new Board of Directors was elected at the first annual meeting of Aging 2000 on March 21, 1995. The by-laws required that each Aging 2000 community group, formerly called consortia, would elect three of its members to the Aging 2000 board, and that at least two had to be consumers. This provision ensured that the "new" Aging 2000 would be a non-profit organization whose governance would be controlled by consumers.

On March 31, 1995, the Aging 2000 Board of Directors voted unanimously to adopt the proposed Consumer Health Care Partnership Model and directed staff to develop a Strategic Plan for its implementation.

THE CONSUMER HEALTH CARE PARTNERSHIP.

A major challenge facing Aging 2000 in the development of the Consumer Health Care Partnership model was explaining to consumers that they would now have to take more responsibility for the direction of the organization. Consumers were active participants from the very inception of Aging 2000, but many of them felt that providers and insurers had a dominant role in the organization's activities.

Even though the Aging 2000 demonstration projects focused on involving consumers in assessing their own health status and participating in the development of their own care plans, most consumers felt that providers were, by and large, running the show. Many consumers believed that the providers and health plans were involved with Aging 2000 to protect their own interests, particularly when it appeared that Ira Magaziner would play a key role in comprehensive national health reform, giving Rhode Island an inside track for a potential Medicare waiver.

So much emphasis had been placed on the need for a federal Medicare waiver to implement Aging 2000's approach to health system reform that it became something of a "Holy Grail" for the organization. Yet there was no clear consensus about what a potential waiver should accomplish. An Aging 2000 Waiver Committee had been working for months with little direction or progress.

The shift in focus from becoming some kind of model health plan or provider network to developing a consumer alliance or advocacy organization, requiring extensive consumer involvement and active participation, was a difficult concept to explain. During the summer of 1995, as the new Aging 2000 Strategic Plan was being developed, the demonstration projects funded by the John A. Hartford Foundation were nearing completion, presenting a significant financial challenge as well.

The key to creating the Consumer Health Care Partnership was convincing consumers that the dramatic changes in Medicare, particularly the impending proliferation of Medicare Managed Care and Medicare Select options, could work to the advantage of Medicare beneficiaries. Consumers needed to understand that increasing competition for their business among a growing number of health coverage options would enable them to use their purchasing power to improve the health care system.

Through dozens of speaking engagements throughout the state before a broad range of senior groups, including AARP chapters, church groups, social clubs, senior centers and various civic organizations, Aging 2000 staff conveyed the message that the changing Medicare program would offer greater choice to consumers, that increasing competition among plans would reduce cost and expand coverage, and that through Aging 2000's efforts, Medicare beneficiaries could become educated consumers capable of making informed decisions about their health coverage options.

Aging 2000 also would become a vehicle to encourage competition among health plans and providers on the basis of quality, as well as cost and coverage, by promoting the development of performance measures that would evaluate medical quality, consumer satisfaction and impact on health status. Putting this information into the hands of consumers would improve the overall quality of care available to Medicare beneficiaries in Rhode Island.

Finally Aging 2000 would work with the University of Rhode Island, Brown University and Rhode Island College to develop educational programs and materials for providers and consumers regarding health and aging issues. Providers would learn how to care for seniors more effectively and consumers would accept more responsibility for their own health. Aging 2000's model of an interdisciplinary approach to improving the health of individual consumers would be promoted and tested in cooperation with health plans and providers.

In July of 1995, Rhode Island Governor Lincoln Almond hosted a press conference at the State House at which Aging 2000 announced its new direction. A front page article in the Providence Journal Bulletin by medical writer Felice Fryer described Aging 2000's goal of publishing consumer reports that would provide Medicare beneficiaries and their families with objective comparisons of health coverage options for seniors, and eventually with information about the quality of the care they provide.

The day after the press conference, Aging 2000 directors and staff met with representatives from the John A. Hartford Foundation who, while genuinely impressed with Aging 2000's new direction, made it clear that no additional

funding would be available from them. Existing financial constraints already had reduced staffing to less than four full-time equivalent positions. Now Aging 2000 was faced with running out of money by the end of the year.

In November 1995, following lengthy discussion and review, the Aging 2000 Board of Directors adopted the strategic plan drafted by staff. The plan for implementation of the Consumer Health Care Partnership Model would:

> "allow Aging 2000 to represent the consumer, working with insurers and providers to develop managed care services based on an Aging 2000 model. Consumer-oriented, community-based, preventative and primary care would be emphasized. Aging 2000, under this scenario, would develop a public-private partnership approach to restructuring the health care delivery system, and monitor the scope and quality of services offered to elderly Rhode Islanders" (Aging 2000 Strategic Plan, November 1995:8).

Four components were envisaged in this plan. These functions continued the role of Aging 2000 as an organization of, by, and for elderly Rhode Islanders:

- Health care public policy development and advocacy: the Consumer Health Care Alliance;
- Consumer and provider education and information: the Health Education Resource Center;
- Collection and analysis of clinical information: the Quality Information Management Corporation; and

- Health plan and provider performance reporting and consumer-driven market reform: the Consumer Health Assurance Cooperative.

By being "consumer-driven," Aging 2000 would remain responsive to and reflective of its elderly constituency. Aging 2000 would review health care policy issues, inform consumers and solicit their views, and organize consumer advocacy efforts on issues of concern. Its Health Education Resource Center, would build upon existing educational resources in the state to enhance the education of both consumers and health care providers. Central to the identity and purpose of Aging 2000, the Health Education Resource Center would strengthen and empower the elderly as active participants in addressing their own health care needs and be an excellent resource for providers on health and aging issues.

As 1995 ended, the John A. Hartford Foundation funding ran out. Aging 2000 staff consisted of Executive Director Ed Zesk, Director of Operations Carol Cummins and part-time Medical Director John Stoukides, MD. Yet enthusiasm for Aging 2000's new direction ran high, particularly among consumers who began to grasp the significance of the strategic plan. But Aging 2000 had to begin producing tangible evidence that it could deliver on its promises, especially the pledge to help consumers understand new Medicare coverage options.

In early 1995, under contract with the R.I. Department of Elderly Affairs, Aging 2000 developed a workshop entitled "Understanding Medicare Managed Care." Its purpose was to describe and answer questions about the different types of coverage available to Medicare beneficiaries in the state. From early

1996 through July 1, 1996, 40 workshops were conducted at various locations around the state attended by more than 1000 consumers.

Aging 2000 published its first consumer report on Medicare coverage options in March 1996. Entitled, "It's Your Choice: A Closer Look at the Health Care Coverage Options Available to Rhode Island Seniors Today," the report explained the differences among basic Medicare, Medigap, Medicare Select and Medicare managed care plans available in Rhode Island and compared their costs and coverage.

Thanks to an article in the Providence Journal-Bulletin describing "It's Your Choice," Aging 2000 received more than one thousand telephone requests for the report during the week following the article's publication. Aging 2000 also adopted a formal membership policy for the first time. Since receiving the consumer report was a benefit of membership, Aging 2000 gained nearly 1500 new members in the space of a few weeks.

Although no fee was required for membership, members were encouraged to make donations generating a new source of income for Aging 2000 through member contributions. This gave rise to the hope among some board members, particularly consumer members, that Aging 2000 might some day be largely member supported.

Aging 2000 officers and staff met with government officials and public policy makers, including the members of the Rhode Island Congressional delegation and the directors of the state departments of Health, Elderly Affairs and Human Services, to brief them on the organization's new strategic plan.

Reaction was universally positive and Aging 2000 was strongly encouraged to proceed on its new course.

A key contact was made through members of Congress with HCFA Administrator Bruce Vladeck. In March 1996, Aging 2000 Executive Director Ed Zesk and Board member David Rehm met with Administrator Vladeck, selected members of HCFA staff, and representatives of the Administration on Aging and the Group Health Association of America in Washington D.C. to discuss the goals of Aging 2000 in the context of national Medicare policy issues. Vladeck expressed his interest in the concept of a non-profit consumer organization as a vehicle to educate Medicare beneficiaries about the growing number of health coverage options available to them. He also offered to host a meeting with representatives of health plans in Rhode Island to encourage their cooperation with Aging 2000's efforts.

At Administrator Vladeck's invitation, a meeting was held in his Washington office in April attended by representatives of health plans offering, or planning to offer, Medicare managed care products in Rhode Island. Vladeck pointed out that by supporting Aging 2000's efforts to help Medicare beneficiaries understand all of their health coverage options, the potential market of consumers willing to consider managed care plans would expand.

After a series of follow-up meetings back in Rhode Island attended by Aging 2000, Blue Cross of Rhode Island, Harvard Pilgrim Health Care, United Health Plans of New England and Tufts Health Plan, an agreement was reached that these four plans would financially support 60 additional Aging 2000 Medicare

managed care workshops and the publication of the next "It's Your Choice" consumer report. Significantly, at a press conference on Friday, August 9, 1996, announcing the agreement, not one consumer or reporter questioned whether sponsorship by the plans would compromise the objectivity of the workshops or the consumer report; a testament to the reputation Aging 2000 had established as an objective consumer advocacy organization.

The motivation of the plans in collectively supporting Aging 2000 is difficult to generalize. While some plan representatives seemed to grasp the potential consumer and public relations value in working with a consumer group like Aging 2000, others seemed to participate grudgingly as if they simply didn't want to be left out of the process or be perceived as uncooperative.

Meanwhile, Aging 2000 had been meeting with the National Committee for Quality Assurance (NCQA) regarding its planned expansion of the Health Plan Employer Data and Information Set (HEDIS) performance measurement system to include Medicare managed care plans. NCQA expressed interest in working with Aging 2000 to develop a pilot consumer report for Medicare beneficiaries using its newly developed HEDIS 3.0 Medicare managed care performance measures.

Aging 2000 also took the lead in creating the Rhode Island Quality Care Consortium, a collaborative initiative to improve the quality of care among nursing homes in Rhode Island involving thirteen long-term care facilities, the Brown University Center for Gerontology and Health Care Research, Long Term Care Quality, Inc. and Physician's Quality Care, Inc. Through the consortium,

Minimum Data Set (MDS) information is collected from the participating homes and analyzed to develop reports comparing their performance in a number of areas with each other and against national data.

Three reports were planned at six month intervals. A forum would be conducted in conjunction with the release of each report, at which homes that performed well in selected areas of measurement, would be invited to make presentations to their peers about why they believed they were successful in these areas. The three reports planned for this pilot program were scheduled to be delivered in the Fall of 1996, the Spring of 1997 and the Fall of 1997. Aging 2000 pledged to work with its consumer members to develop an understandable consumer report on the quality of care delivered by the homes compared to national averages using the results of the third report.

In August 1996, Aging 2000 received a "Critical Issues" grant from the Rhode Island Foundation and United Way of Southeastern New England to develop its Peer Mentor program. An outgrowth of the demonstration projects, Peer Mentors are retired health care and social services professionals who are recruited and trained by Aging 2000 to provide one-on-one counseling to individuals in need of assistance in dealing with personal health care or emotional problems. Peer Mentors are assigned by Aging 2000 to local health and social service agencies in their communities and spend an average of two to four hours a week working with clients.

The Rhode Island Geriatric Education Center (RI/GEC), a partnership among Aging 2000, the University of Rhode Island, Rhode Island College, and

Brown University, received a three-year grant in September, 1996, from the federal Bureau of Health Professions. This funding enabled the partner organizations to begin developing educational programs designed to improve knowledge and skills in geriatrics and gerontology among health care providers in Rhode Island.

The emphasis of the RI/GEC is interdisciplinary care team education and training for physicians, nurses, social workers, pharmacists and other health care professionals. The goal is to promote a collaborative approach to caring for elderly Rhode Islanders throughout the entire health care delivery system.

Also in September 1996, Aging 2000 was awarded a contract by the Health Care Financing Administration (HCFA) to draft a report, in the form of a case study, describing the development and operation of the Aging 2000 organization. The contract reflects a growing interest outside of Rhode Island in Aging 2000 as a potential model for other communities of a Medicare consumer education and information initiative run by consumers themselves.

At the request of American Association of Health Plans President Karen Ignani, Aging 2000 Executive Director Ed Zesk drafted an article for the Association's "Healthplan" magazine describing the collaborative relationship between Aging 2000 and Medicare managed care plans in Rhode Island to promote consumer information. Numerous other articles began appearing in various health care trade publications regarding Aging 2000's efforts.

Throughout the fall of 1996, Aging 2000 fielded queries from health plans, providers, and consumer groups around the country interested in promoting

similar initiatives in their respective communities. For example, the Greater Detroit Area Health Council, the Oakwood Health Care System, and Hospice of Michigan began developing a fledgling Aging 2000 of Southeastern Michigan with Aging 2000's assistance.

A number of small grants and corporate contributions were given to Aging 2000 in the fall of 1996 to develop educational programs designed to help consumers understand the impact of the aging process on health and to help them use the health care system more effectively.

The challenge for Aging 2000 was to secure more significant, long-term funding that would allow the organization to fully develop the components of the Consumer Health Care Partnership concept. Fortunately, Pfizer, Inc. was among the organizations that heard of Aging 2000 and expressed an interest in its collaborative efforts with health plans as well as its consumer and provider educational programs.

Following a series of meetings at its headquarters in New York City during the Fall of 1996, Pfizer awarded $300,000 in funding to Aging 2000 for the period of November 1996 through December 1997. Pfizer clearly saw the potential value of a consumer organization as a vehicle to work with health plans and providers on issues of common interest, and as a credible and objective source of information and education for consumers.

Pfizer's support enabled Aging 2000 to hire the staff needed to fully develop and implement its consumer education programs, strengthen its

grassroots, community-based organizational structure and provide assistance to other communities interested in creating similar initiatives.

As 1997 began, Aging 2000's situation had improved significantly. Its finances were stable, due largely to Pfizer funding, and three new staff positions, Education Coordinator, Volunteer Coordinator, and Office Manger, were filled. Consumers, providers, health plans, government officials and other media all seemed to grasp basic concepts of Aging 2000's new direction.

The National Council on Aging (NCOA) invited Aging 2000 to become a charter member of its newly-created National Coalition of Consumer Organizations on Aging (NCCOA) and Aging 2000 Executive Director Ed Zesk was asked to give a presentation at NCOA's March meeting in Chicago.

Contributions from Rhode Island based corporations such as Fleet Bank and CVS Pharmacy indicated Aging 2000's growing credibility with the business community. The second "It's Your Choice" consumer report on health coverage options for Medicare beneficiaries in Rhode Island was made available by CVS in all of its pharmacies statewide. The CVS partnership made it possible for 18,000 copies of "It's Your Choice" to be distributed to Rhode Island consumers. A second printing of the report had to be ordered to provide enough copies for Aging 2000's ongoing "Understanding Medicare Managed Care" workshops.

As Aging 2000's membership swelled to nearly 3000, the role of the community groups became even more important as a vehicle for consumer involvement. The transition from consortia to community groups was not always easy.

The consortia activities had been focused primarily on the Aging 2000 demonstration projects. Under the Consumer Health Care Partnership Model, the community groups function more as a means of communicating with consumers and getting their input on a grassroots level.

Community groups were encouraged to appoint their own steering committees with consumer and provider co-chairs. They were asked to schedule Aging 2000 consumer educational programs in their communities and appoint representatives to all Aging 2000 standing committees.

A unique feature of Aging 2000 educational workshops is that they are facilitated by consumer volunteers recruited and trained by Aging 2000. A number of workshops were developed, with consumer input, addressing a broad range of health and aging issues. Retired health care, social service and education professionals were recruited as workshop leaders to run these programs in their communities. This approach resulted in significant credibility for Aging 2000's consumer education initiatives. Participant response has been overwhelmingly positive.

At the suggestion of Senator John H. Chafee (R-RI), Aging 2000 applied for and received a two-year grant from the Administration on Aging to educate consumers about health care waste, fraud, and abuse. Aging 2000 hired Susan Fine, JD, MPH, formerly the Governor's policy advisor on health care, to run the project.

In July, 1997, Aging 2000 held its Annual Membership Meeting sponsored by the Providence Journal-Bulletin. Ms. Michael McMullen, the Director of

HCFA's Center for Beneficiary Services, Governor Lincoln Almond and Senator Jack Reed (D-RI) were the main speakers. The focus of the meeting was on the dramatic changes taking place in the Medicare program and the role of Aging 2000 in helping Medicare beneficiaries in Rhode Island cope with those changes.

That summer, the National Council on Aging (NCOA) approached Aging 2000 to be a partner agency in exploring the potential of NCOA's Medicare Consumer Cooperative concept. The Medicare Consumer Cooperative would be a vehicle for Medicare beneficiaries on the local level to combine their purchasing power and exert direct influence over the competition among health plans and providers in the market, and make them more responsive to consumer demands.

On November 10, 1997, the Rhode Island Quality Care Consortium publicly released the results of its year-long pilot program to improve the quality of care among its 13 participating nursing homes. The results clearly showed the effectiveness of sharing outcomes data on nursing home performance and providing educational forums designed to help them improve.

Overall performance among the participating homes improved measurably, and their aggregate performance was consistently superior to national averages by the end of the pilot program. A consumer version of the report was published by Aging 2000.

As a result of this initiative, Rhode Island Quality Partners (RIQP) the state's peer review organization, approached Aging 2000 with a proposal that RIQP join the consortium and partner in a continuation and expansion of the program. RIQP also expressed an interest in working with Aging 2000 to expand

the consortium's efforts to evaluate the performance of Medicare managed care plans, hospitals and other providers.

Aging 2000's credibility as a representative of Medicare consumer interests on health and aging issues was further enhanced by increasingly collaborative relationships with state agencies including the Rhode Island Departments of Health, Human Services, and Elderly Affairs, the Long Term Care Coordinating Council and the Governor's Advisory Council on Health. Aging 2000 also co-sponsored educational efforts with the Governor's Advisory Council on Aging, RI Forum on Aging, and the AARP.

Aging 2000 was asked by the RI Department of Elderly Affairs to help develop a statewide coalition on health promotion for the elderly. The coalition members including departments of state government, providers, and institutions of higher learning agreed that Aging 2000 should be the lead agency because of the credibility it had established as an objective source of consumer education programs, as well as its history of coalition building.

By late 1997, Aging 2000 had successfully established itself as an effective leader in addressing health care issues for seniors. Consumers had become actively involved in Aging 2000 governance and operations by serving as board and committee members, participating in community group activities and volunteering as Peer Mentor or workshop leaders.

Health plans, providers, state government agencies, elected officials, and other interested parties actively sought closer working relationships with Aging

2000. The organization's national reputation was growing as was interest among other communities in replicating Aging 2000's efforts.

Although future long term, stable funding was still an issue, interest among private foundations, state and federal government agencies, and the RI congressional delegation in providing such funding continued to grow. Aging 2000's position is that consumer education and information programs for Medicare beneficiaries should be federally funded but conducted at the local level.

The biggest challenge for local non-profit consumer organizations is not only to build upon the grassroots, community-based structure but also to reach the general public. In late 1997, Aging 2000 reached an agreement with the Providence Journal-Bulletin, the major statewide daily newspaper, and WJAR-TV, a NBC affiliate and the predominant television station in Rhode Island, to conduct a series of quarterly statewide consumer education and information programs in 1998.

The programs will address a number of critical issues for elderly consumers including Medicare reform; home and community based care; health care waste, fraud and abuse; and long term care issues. They will feature comprehensive media coverage of these issues jointly promoted by the Journal and WJAR-TV, and include quarterly reports published as an insert in the Sunday edition of the paper reaching approximately 250,000 households.

Aging 2000 believes that this joint initiative with major print and broadcast media can serve as a model for other communities. Our goal for 1998 and

beyond is to expand our efforts to implement the Consumer Health Care Partnership for Medicare beneficiaries in Rhode Island, and to help other interested communities to develop and implement similar efforts.

CONCLUSION.

From its beginning as Magaziner's bold idea to radically reform the entire system of health care for the elderly in Rhode Island to its continued emphasis on community grassroots involvement and direction, Aging 2000 has maintained basic core principles and goals in its activities. As it has evolved, it has gained broad participation and critical experience. It started by understanding the system non-judgmentally via diverse points of view and recommending principles of care by consensus. It catalyzed community-based groups of existing agencies, institutions, providers, and consumers to collaborate with health plans and providers in order to implement model demonstrations of the core principles. Finally, it has become the Aging 2000 Consumer Health Care Partnership using the purchasing power of Medicare beneficiaries to achieve market-driven improvements in the quality and scope of care in a highly competitive environment. Consistently focused on older adults as consumers and active participants throughout its history, Aging 2000 continues to help elderly people shape and choose their health care.